

Original article

Stress in parents of children with developmental disabilities

Andrijana Bakoč, Olivera Kalajdžić, Ranka Perućica, Ivana Zečević

University of East Sarajevo, Faculty of Medicine Foča, Republic of Srpska, Bosnia and Herzegovina

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Corresponding author:

Andrijana Bakoč, Assist. Professor Studentska 5, 73300 Foča e-mail: andrijana.bakoc@ues.rs.ba

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Summary

Introduction. The birth of a child with developmental disabilities changes the life of a family, placing before it additional obligations, greater responsibility and facing numerous challenges that can lead to an increase in parental stress. The aim of this research is to examine the level of stress in parents of children with developmental disabilities and determine the difference in stress intensity in relation to individual characteristics of parents (sex, age, educational and work status) and children (type of disability).

Method. The sample consisted of 122 respondents, active members of the association of parents of children with developmental disabilities from Eastern Herzegovina and the Sarajevo-Romania region. In the sample, a higher percentage was female respondents (78.72%), while the average age of the respondents was 46.97 years (SD = 12.04). For the purpose of data collection, a sociodemographic guide and the Stress Symptoms Scale –16 were used.

Results. The subjects of our sample tended to experience a relatively low level of stress (Mdn = 26.5). There were no statistically significant differences in the stress intensity of parents of children with developmental disabilities in relation to sex, age, work, and education status of the respondents. On the other hand, the statistically significant difference was found in the level of stress manifestation in relation to the type of child's disability (p = 0.01), whereby parents of children with multiple disabilities experienced the greatest stress, and parents of children with chronic diseases and physical disabilities experienced the least stress.

Conclusion. The results indicate the importance of studying this issue in future research in order to empower the families of children with developmental disabilities and reduce parental stress.

Keywords: parents, stress, children with developmental disabilities

Introduction

Stress is an inevitable factor in every individual's life, particularly in today's era characterized by significant changes, challenges, and a fast-paced lifestyle. One definition of stress is that it is a negative emotional experience accompanied by predictable physiological, cognitive, and behavioral changes leading to alterations in the perception of a stressful situation and the ability to cope with it [1].

Parental stress is defined as the stress parents experience not only due to raising a child, but also because of social and environmental circumstances, responsibilities, and the demands of daily life [2]. Furthermore, parental stress can be described as stress that arises when the parents' perception of the demands of parenting exceeds their resources to cope with them [3].

The family is considered an irreplaceable environment in which a child is shaped into a person, allowing him/her to meet the most important needs. The birth of the child with developmental disabilities changes the life of the family, imposing additional obligations, greater responsibilities, and the need to face numerous challenges. As a result, for most parents, raising the child with developmental disabilities can be extremely stressful.

In this regard, it is not surprising that research findings show that parents of children with developmental disabilities experience high levels of stress [1, 4, 5, 6, 7], particularly when this stress is compared to the levels experienced by parents of typically developing children [8, 9, 10, 11, 12, 13, 14].

In addition to its adverse effects on parents' ability to care for their child, stress also negatively impacts parents' mental and physical health, as well as the quality of the parent-child relationship [16]. Comprehensive reviews of studies analyzing the impact of chronic stress on health outcomes for parents of children with developmental disabilities reveal that stress has a negative effect on parents' health, particularly in mothers [16]. Research by other authors also indicates that stress can affect the quality of the parent-child relationship and has a detrimental impact on parents' psychological well-being [17, 18, 19].

The sources of stress are varied. One significant source is the caregiving itself, as most children with developmental disabilities require assistance with basic daily activities such as feeding, toileting, bathing, and similar tasks. The increased supervision needed requires more time and patience, which can be stressful and frustrating for parents [20, 21]. Furthermore, sources of stress also include dealing with social stigmatization and additional financial burdens [21, 22, 23, 24].

Parental stress can also be linked to the degree of disability in the child, particularly when it comes to challenging behaviors, as these children require constant supervision, thus depriving parents of the time needed for their daily activities [25]. The literature shows higher levels of parental stress among parents of children with autism spectrum disorder [27, 28, 29] and parents of children with attention deficit hyperactivity disorder (ADHD) [14, 29].

In addition to these factors, authors suggest that parental stress levels are also influenced by certain characteristics of the parents, such as socioeconomic status, level of education, age, sex, and others [1, 30, 31].

When it comes to research findings regarding differences in stress levels based on parents' socio-economic and educational status, there is no consensus in the literature. In some studies, socio-economic and educational statuses do not appear to influence differences in parental stress levels [12, 32, 33]. On the other hand, some studies show that parents of children with developmental disabilities with higher educational levels and better socio-economic status tend to experience higher levels of stress compared to parents with lower educational levels and worse socio-economic status [4, 34, 35]. Additionally, there are findings suggesting that parents with more lucrative and prestigious occupations experience higher levels of stress than parents in less prestigious jobs, regardless of their income [36].

When it comes to sex differences in the level of stress experienced, the results are inconsistent. Some studies suggest there are no differences in stress levels based on sex among parents of children with developmental disabilities [4, 12, 32], while others indicate that mothers experience higher levels of stress [13, 27, 33, 37]. Less common are findings indicating that fathers may experience higher levels of stress [12, 28]. Some studies show that the age of parents is a significant factor correlating with the level of parental stress. Older parents (over 40 years of age) may be more concerned with meeting the needs of their child with developmental disabilities and, as a result, experience higher levels of stress [5, 38].

The goal of this study is to examine the level of stress in parents of children with developmental disabilities and identify differences based on specific parent characteristics (sex, age, educational and employment status) and child characteristics (type of disability).

Method

Sample

The sample consisted of 122 parents of children with developmental disabilities, active members of the association of parents of children with developmental disabilities from the regions of Eastern Herzegovina and the Sarajevo-Romanija area (Foča, Višegrad, Trebinje, Bileća, Gacko, Nevesinje, Rogatica). The sample included a higher proportion of female participants (78.7%) compared to male participants (21.3%). The average age of the

Table 1. Sociodemographic characteristics of participants

participants was 46.97 years (SD = 12.04). Sociodemographic characteristics of the participants are presented in table 1.

Research Instruments

A brief sociodemographic questionnaire was used in the study to obtain information about the sex and age of the child, sex and age of the parents, their level of education, employment status, and the type of disability the child has. To assess the level of stress, the Stress Symptom Scale - 16 [39, 40] was used. This scale is a modified version of the "Measure of Strain" [41]. The five-point Likert scale was used to indicate symptoms that were typically associated with excessive environmental demands, individual's physiological and mental resources, or the overload of those resources. The participants were asked to rate how much (from "not at all" to "very much") each of the 16 symptoms from the list disturbed them during the past year. The original version of the instrument shows satisfactory internal consistency reliability ($\alpha = 0.85$). After modifications, the scale demonstrated satisfactory reliability as well (α = 0.86, test-retest reliability = α = 0.83). In our sample, the Cronbach's

	Sample	N	%
Parental sex	Male	26	21.3
	Female	96	78.7
Age group	Younger (<45 g)	63	51.6
	Older (≥45 g)	59	48.4
Employment status	Employed	41	33.6
	Unemployed	81	66.4
Parental education	Primary school	23	18.9
	Secondary school	80	65.6
	University degree	19	15.5
Type of disability in the child	Intellectual disability	23	18.8
	Hearing, speech, and voice disorders	18	14.8
	Chronic illness and physical disability	29	23.8
	Multiple disabilities	52	42.6

alpha coefficient was calculated to determine the internal consistency, showing a high level of reliability ($\alpha = 0.91$).

Research procedure

At the beginning of the research (Phase 1), contact was established with representatives from all associations of parents of children with developmental disabilities in the regions of Eastern Herzegovina and the Sarajevo-Romanija area. The goal and methodology of the research were thoroughly explained. After the representatives of the associations expressed their consent to carry out this type of research, the study proceeded to the second phase, during which data were collected about the number of parents of children with developmental disabilities. The next phase involved the distribution of the questionnaires. Each association had one designated person responsible for distributing the questionnaires to parents, contacting the researchers, and collecting the completed instruments. The instruments were sent to the researchers via mail. Out of a total of 150 distributed questionnaires, 135 were returned; however, due to missing data in some of the responses, 122 instruments were included in the final analysis. The final phase involved the analysis of the collected data.

Data processing

Statistical data analysis was performed using the SPSS (Statistical Package for the Social Sciences, version 23) software package. To assess the normality of the distribution of scores, the Kolmogorov-Smirnov test was applied, which showed that the data deviated from a normal distribution (p < 0.001). Therefore, to present the descriptive parameters, the median, as well as the minimum and maximum values, were used. For comparing the examined variables, the Mann-Whitney U test and the Kruskal-Wallis test were employed.

Results

After data processing, the analysis was conducted to assess the level of stress in parents of children with developmental disabilities and to determine the differences based on sociodemographic characteristics of the parents and the type of disability in the child.

The data analysis presented in figure 1 shows that the participants in our sample tend to experience relatively low levels of stress, as reflected in the median value (Mdn = 26.50). The scores obtained ranged from a minimum value of 17 to a maximum value of 67, which was significantly lower than the maximum theoretical value of 80.

The data presented in table 2 indicate that there are no statistically significant differences in the intensity of stress in parents of children with developmental disabilities based on sex, age, or employment status.

The application of the Kruskal-Wallis test revealed statistically significant differences in the intensity of stress among parents of children with developmental disabilities based on the type of disability (p = 0.01). Subsequent analysis using the Mann-Whitney U test and Bonferroni correction (where p < 0.012 is considered significant) showed the statistically significant difference in stress levels between parents of children with chronic illnesses and physical disabilities and parents of children with multiple disabilities (p < 0.001). Based on the median values, it is evident that parents of children with multiple disabilities experience higher levels of stress (Mdn = 33.50) compared to parents of children with chronic illnesses and physical disabilities (Table 3).

No statistically significant differences were found in the level of stress experienced by parents of children with developmental disabilities based on the educational status of the parents. This finding did not require further post-hoc testing (Table 4).



Figure 1. Distribution of overall stress in parents of children with developmental disabilities

	hic characteristics of ondents	Mdn	Min	Max	Mann-Whitney U Test	Z	р
Sex	Male	32,00	17	67	1011,00	-1.48	0.19
	Female	25,00	17	59			
Age	Younger	25,00	17	62	1740.00	-0.61	0.54
	Older	27,00	17	58			
Employment	Employed	28,00	17	59	1438.50	-0.79	0.43
status	Unemployed	26,00	17	67			

Table 2. Differences in stress levels based on parents' sociodemographic characteristics

Table 3. Differences in stress levels based on the type of disability in the child

Scale	Type of child's disability	Mdn.	Min.	Max.	Mann-Whitney U Test	ID	HSVD	CIPS
	ID	29.00	18	59	U Z P			228.00 -1.95 0.05
Scale	HSVD	24.00	18	40	U Z P	136.00 -1.87 0.06		240.00 -0.46 0.64
Stress	CIPS	21.00	17	67	U Z p	228.00 -1.95 0.05	240.00 -0.46 0.64	
	MD	33.50	17	58	U Z p	552.00 -0.53 0.60	312.00 -2.10 0.04	456.00 -2.94 0.003

Values of the Kruskal-Wallis rank test: $\chi^2 = 11.37$, df = 3, p = 0.01 ID = Intellectual disability, HSVD = Hearing, speech, and voice disorders, CIPS = Chronic illnesses and physical disabilities, MD = Multiple disabilities

Scale	Educational status	Mdn.	Min.	Max.	χ^2	df	Р
Stress Scale	Primary school	29.00	18	58		2	0.25
	Secondary school	25.50	17	67	2.75		
	University degree	27.00	17	59			

Table 4. Differences in stress levels based on parents' educational status

Discussion

The results of this study indicated that parents of children with developmental disabilities experienced a relatively low level of stress. These findings are consistent with the results of the study by Simo and colleagues [42], which examined stress levels in parents of children with autism spectrum disorder. In that study, the majority of participants reported experiencing low levels of stress (55.6%). The authors suggested that such a finding could be due to response bias or the diversity of family responses to potentially stressful situations. Similar results were found in a Malaysian study conducted on the sample of 110 parents of children with learning difficulties. The analysis revealed that 80.9% of parents reported average to low levels of stress, compared to only 19.1% of parents who considered themselves to be under higher stress [34]. In contrast, there are many studies that report higher levels of stress in parents of children with developmental disabilities [1, 4, 5, 6, 7]. Considering this, we believe that the obtained results may be influenced by the characteristics of the participants included in the sample, such as the sample size, as well as the age and type of disability of the children. Other authors, in addition to the previously mentioned factors, also emphasize the importance of the instruments used to measure stress levels [28, 43].

The results showed that there were no statistically significant differences in the intensity of stress experienced by parents of children with developmental disabilities based on sex, age, employment status, or educational status of the participants in our sample. The findings regarding the absence of differences in stress between mothers and fathers aligned with results from other studies [4, 12, 32]. On the other hand, these results did not support the widely held belief or empirical findings suggesting that mothers tended to experience higher levels of stress, given that they were often the primary caregivers and were generally more emotionally attached to their children than fathers [13, 27, 33, 37].

In our study, older participants tended to experience slightly higher levels of stress compared to younger participants, although those differences did not reach statistical significance. Nonetheless, we can observe a trend suggesting that older parents may experience higher levels of stress, which is often linked to greater concern about meeting the needs of the child with developmental disabilities [5, 38]. This finding aligns with results from a Spanish study, where the age of parents was not associated with stress levels in parents of children with developmental disabilities [31], which is consistent with our own findings.

Regarding the results of examining differences in stress intensity based on employment status, our findings aligned with those of a Croatian study, where the employment status of mothers was not identified as a significant predictor of perceived stress [14], as well as with other international studies [19, 31, 32].

The previously mentioned study by Croatian authors also showed that the educational status of parents was not a significant predictor of stress levels [13], which is consistent with the findings of this research. Identical results have also been obtained in other studies [31, 32]. In contrast to the results found in our study, the literature also presents findings suggesting that unemployed parents, as well as those with lower levels of education, experience higher levels of stress [44, 45]. It is believed that parents with lower levels of education are more likely to face various socio-economic difficulties, such as unemployment, financial problems, and similar challenges, all of which can contribute to increased stress levels [46].

One of the potential factors influencing the expression of stress in parents of children with developmental disabilities is the severity of the child's impairment [25]. Our results confirmed this assertion, as higher levels of stress were observed among parents of children with multiple disabilities compared to parents of children with other types of disabilities. However, the difference was statistically significant only when comparing the stress levels of these parents to those parents of children with chronic illnesses and physical disabilities. Those findings aligned with the results of a study conducted on the sample of 515 parents who had a family member with an intellectual disability. According to that study, characteristics associated with individuals with intellectual disabilities, such as the presence of co-occurring health problems and the severity of the intellectual impairment, contributed to predicting parental stress, even when other family factors were taken into account [31]. Co-occurring disabilities have also been identified as a significant predictor of parental stress in a study on children with autism spectrum disorders [45]. These results are often explained by the fact that children who require more care demand greater parental engagement, patience, and attention, which in turn reduces the time available for parents to complete their everyday activities [20, 21]. A study with somewhat different results

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was conducted on the sample of 134 parents of children with physical disabilities, intellectual disabilities, and hearing impairments. The findings showed that parents of children with physical disabilities experienced the highest levels of stress, while parents of children with hearing impairments reported the lowest stress levels [1].

The main limitation of this study is the relatively small number of participants included in the sample, as well as the unevenness of the sample in relation to the type of disability in the child. In addition, we must not overlook the possibility that the participants may have been biased when providing their responses. Furthermore, the study did not address other factors that could influence parental stress, such as family support (both formal and informal), which has been identified as one of the most significant protective factors in managing stress in parents of children with developmental disabilities [47, 48, 49].

Conclusion

Parents of children with developmental disabilities exhibit a low level of stress. Parents of children with multiple disabilities represent the highest-risk group when it comes to the level of experienced stress, regardless of the parent's sex, age, employment, or educational status.

Despite the recorded low-intensity stress, we believe it is important to continue providing support to parents and work on strengthening families that have the member with developmental disabilities. Furthermore, in order to obtain new and more relevant data, future research on this topic is necessary, incorporating additional factors that may represent potential sources of stress.

and informed consent was obtained from all individual respondents. The research was conducted according to the Declaration of Helsinki.

Conflicts of interest. The authors declare no conflict of interest.

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Stres kod roditelja djece sa smetnjama u razvoju

Andrijana Bakoč, Olivera Kalajdžić, Ranka Perućica, Ivana Zečević

Univerzitet u Istočnom Sarajevu, Medicinski fakultet Foča, Republika Srpska, Bosna i Hercegovina

Uvod. Rođenje djeteta sa smetnjama u razvoju mijenja život jedne porodice stavljajući pred nju dodatne obaveze, veću odgovornost i suočavanje sa brojnim izazovima što može dovesti do povećanja roditeljskog stresa. Cilj ovog istraživanja je ispitivanje nivoa stresa kod roditelja djece sa smetnjama u razvoju i utvrđivanje razlike u intenzitetu stresa u odnosu na pojedine karakteristike roditelja (pol, starosno doba, obrazovni i radni status) i djece (vrsta smetnje).

Metod. Uzorak su činila 122 ispitanika koji su aktivni članovi udruženja roditelja djece sa smetnjama u razvoju sa područja Istočne Hercegovine i Sarajevsko-romanijske regije. U uzorku su veći procenat činili ispitanici ženskog pola (78,72%), dok je prosječno starosno doba ispitanika iznosilo 46,97 godina (SD = 12,04). U svrhu prikupljanja podataka korišćen je sociodemografski upitnik i Skala simptoma stresa – 16.

Rezultati. Ispitanici imaju tendenciju doživljavanja relativno niskog nivoa stresa (Mdn = 26,5). Nisu dobijene statistički značajna razlike u intenzitetu stresa roditelja djece sa smetnjama u razvoju u odnosu na pol, starosno doba, radni i obrazovni status ispitanika. S druge strane, pronađena je statistički značajna razlika u nivou ispoljavanja stresa u odnosu na vrstu smetnje djeteta (p = 0,01), pri čemu najveći stres doživljavaju roditelji djece sa višestrukim smetnjama, a najmanji roditelji djece sa hroničnim bolestima i tjelesnim invaliditetom.

Zaključak. Rezultati ukazuju na važnost proučavanja ove problematike i u budućim istraživanjima, a sve u cilju osnaživanja porodica djece sa smetnjama u razvoju i smanjivanju roditeljskog stresa.

Ključne riječi: roditelji, stres, djeca sa smetnjama u razvoju